

State Council on Developmental Disabilities/Area Board 6

Annual LQA Trends, Issues, and Needs Report FY 2005-06

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LQA Summary Data: Trends, Issues and Needs

FY 2005/06

Introduction

Since 1997, the Area VI Board has conducted Life Quality Assessments (LQA's) for individuals who use regional center services in the area of Amador, Calaveras, San Joaquin, Stanislaus, and Tuolumne counties. The assessments, or LQA's, are intended to capture the individual's perspective on the quality of his or her life, in order to enrich the individual's planning process (IPP). Summaries are routinely conducted for persons who live in situations other than with their family of origin. However, any regional center client can request and receive an LQA visit.

In addition to the individual planning process, the LQA summaries provide an overall view of the issues, concerns, and needs experienced by eligible adults and children with developmental disabilities. As part of the State Council on Developmental Disabilities' mandate to identify issues and needs for persons with developmental disabilities, the LQA Summary data results have also been reviewed in aggregate.

Just as the individual summaries are intended to contribute to, but not supplant, an overall planning process, so this report is intended to be one tool in the information gathering and assessment process that underlies effective resource development. LQA data is highly subjective, reflecting as much as possible the individual's self perceptions at the time of the visit. The more successful the visitor is in catching that perception, the more useful the LQA is in informing the individual's planning team of personal needs and concerns. Trends in aggregate data represent common experiences, and as such, provide vital insights into the service system and generic support systems in our communities.

Project Design

The format, methods, and standards for conducting LQA visits were developed by the Department of Developmental Services (DDS), and are standardized throughout the State of California. This project relies primarily on trained volunteers, who receive a stipend for completing summaries. They are expected to generate over 12,000 volunteer hours over the duration of this three year project cycle. The project is staffed by two Community Program Specialist positions and a half-time Office Assistant.

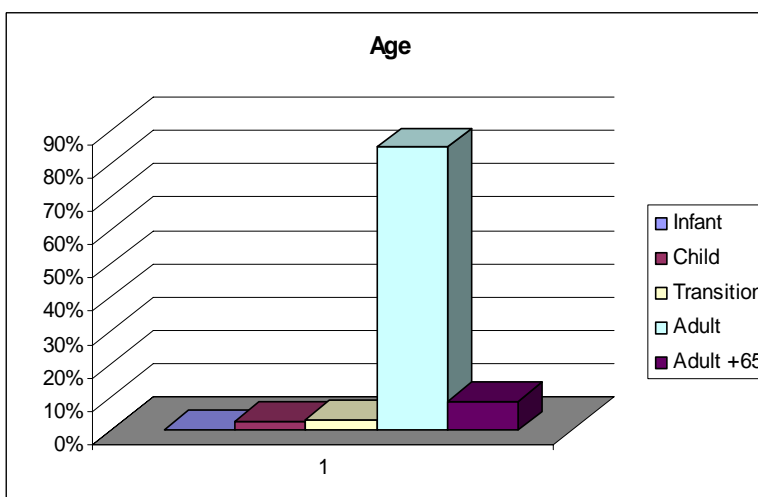
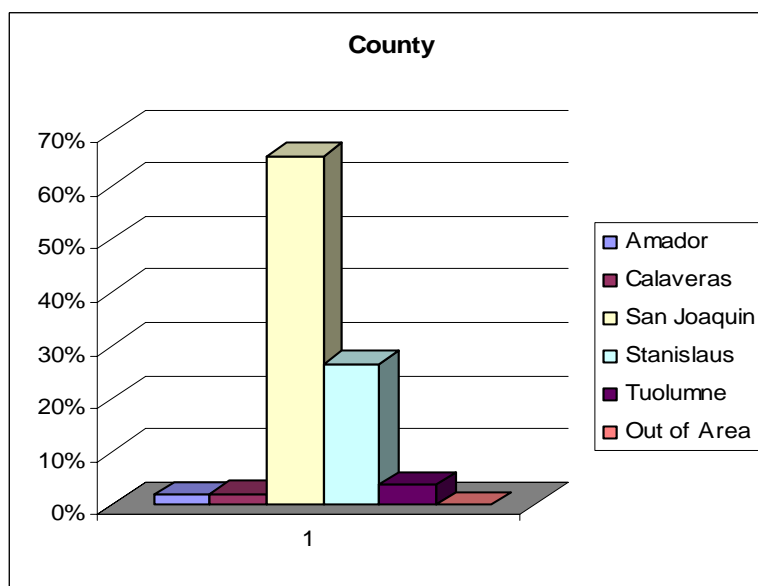
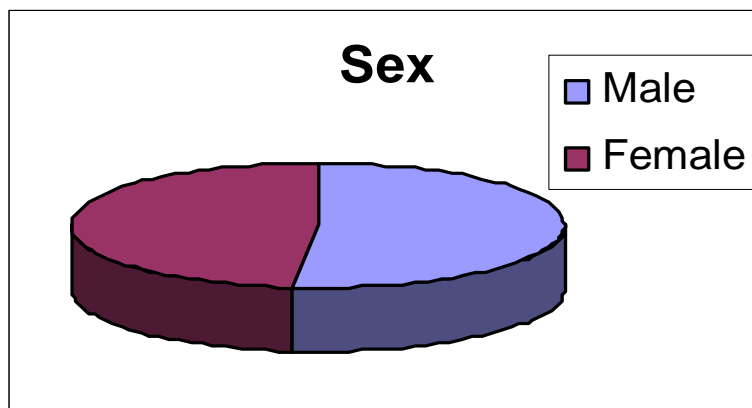
LQA Summary Results

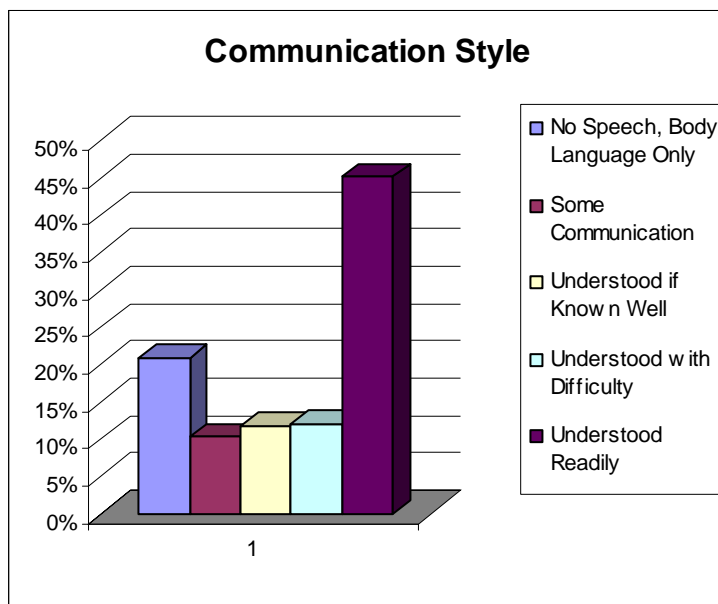
The LQA process looks at 25 life outcomes, grouped into six areas. For each outcome, the visitor indicates either "OK at this time" or "Needs Follow-up", and then documents the observations and comments that explain their conclusions. "Needs Follow-up" is indicated for several reasons. The visitor may not have been able to observe any information about that particular outcome, so the status is unknown. "Needs Follow-up" can also reflect known issues that are being addressed but not fully resolved, or issues that most probably can't be changed but rather reconciled, such as physical losses related to aging. Response to "Needs Follow-up" issues is the responsibility of the regional center and individual planning teams.

Overview

Visitors and LQA staff completed 556 visits, and attempted to complete an additional 326 visits. These attempted visits were not completed for a variety of reasons, such as a major illness or incarceration. People also declined to have visits. Some people declined because they felt their lives were going very well. Others declined for a variety of personal reasons, such as work or family demands. Valley Mountain Regional Center (VMRC) Service Coordinators were helpful in efforts to make contact. By far the majority of service providers were also very supportive of each person's right to have a Life Quality visit.

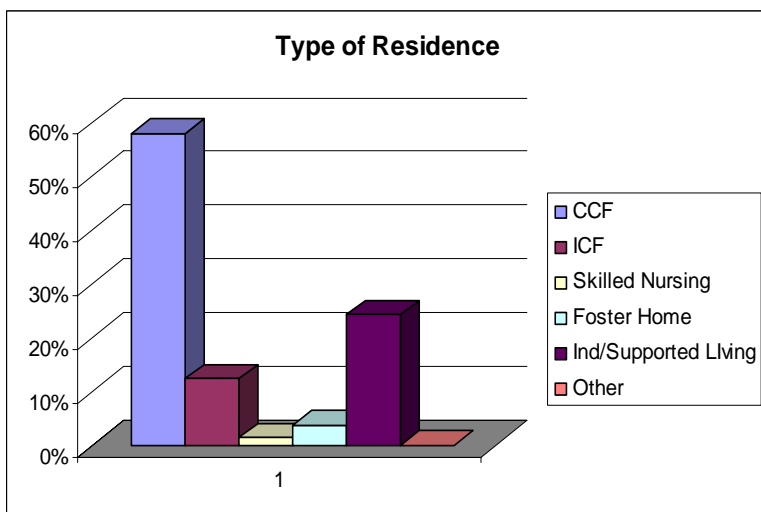
As in previous years, visitors found that most of the people they visited are in safe situations and that their basic needs are supported successfully. The living arrangements and supported day time activities varied through a wide range of service options. Visits were conducted in all five counties of the VMRC catchment area, and both adults and children living in situations other than with their family of origin were visited. Individuals who were visited during the FY02-03 cycle were contacted again for repeat visits this year. Visitors again found that many issues raised in the previous visit had been addressed, particularly those who had had potential rights violations. The overall pattern of services for most people had not changed significantly.



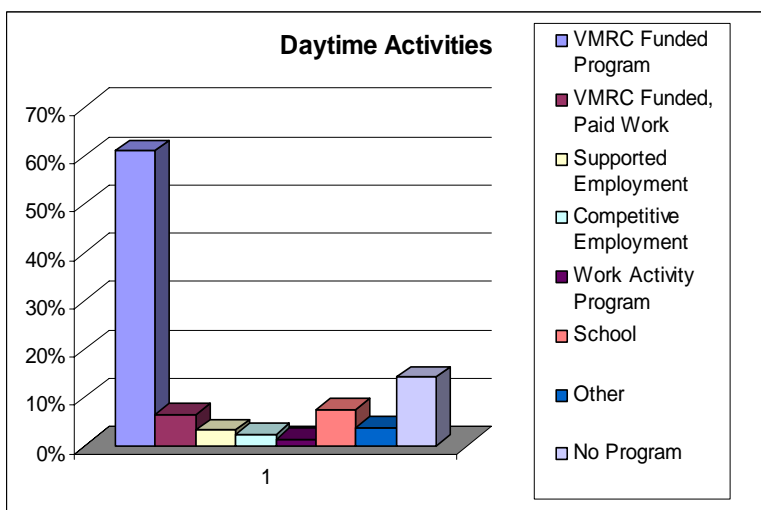


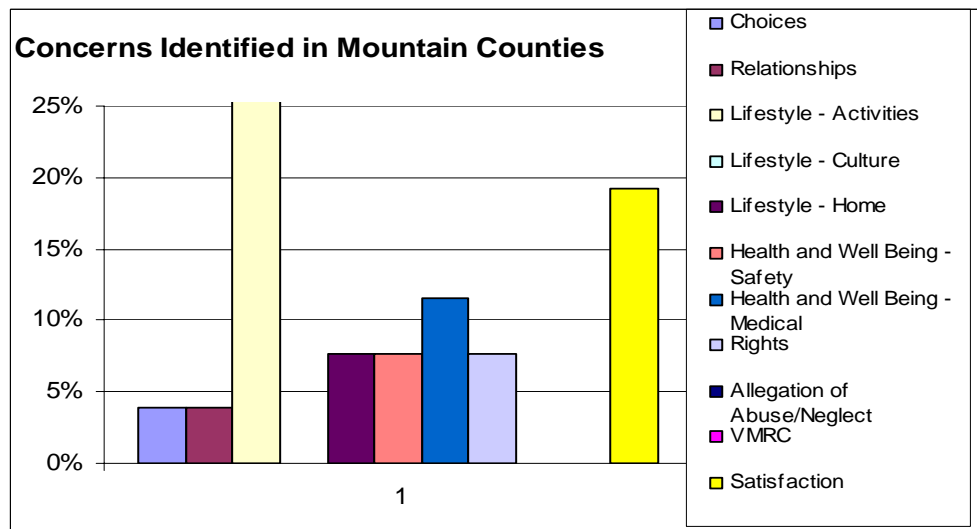
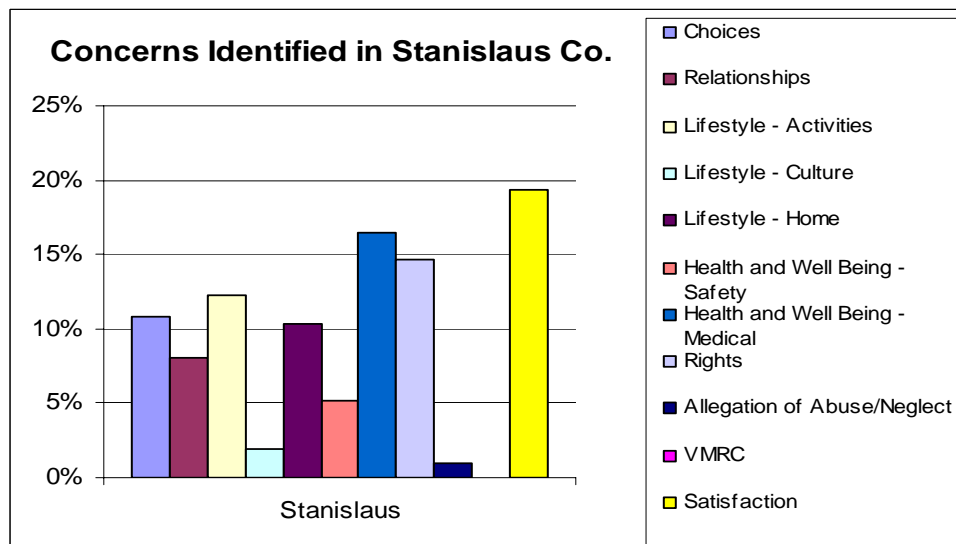
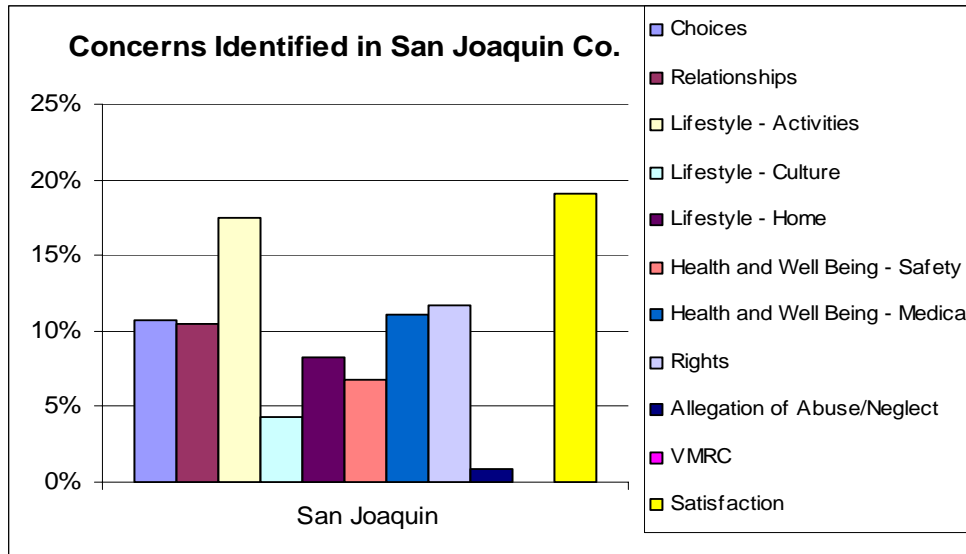
The majority of people visited lived in a community care facility, ranging from 6 beds up to 49 beds in size. They attended a regional center funded program. That majority represents not only the most common circumstance for VMRC clients, but are also the people most likely to agree to a visit. People living independently were mostly likely to refuse a visit or were unable to be contacted.

With the exception of a small attendance at other publicly funded programs such as community colleges, and adult day treatment, adult daytime activities were primarily funded by the regional center. Only 3% of people visited in the five counties used supported employment services.



The same patterns of concerns emerged again this year, suggesting underlying common causes. Many concerns, such as problems with safe and decent rental housing are common to poverty. Some concerns are certainly common in the shared human experience, such as longings for closer family ties and friendships. As in previous years, people in the mountain counties tended to express a greater sense of autonomy and satisfaction overall. However, the mountain counties were also characterized by a natural screening effect, as people who have more problematic support needs tended to congregate in urban communities.





Emerging Trends

Thirty-eight percent of the people visited identified no follow-up needs. The percentage was 41% during the FY 2003-04. The majority of those who identified follow-up needs had less than three issues. Many issues were life enrichment concerns, such as learning new life skills. While areas for system improvement continue to emerge, the foremost observation is that the majority of people visited are greatly or mostly satisfied with services they receive.

Residential Services

Visitors found a similar pattern of dissatisfaction with care homes again this year. Thirty-six individuals visited expressed a desire to move from their current carehome. Many wanted to move to different areas or to move to a less restrictive setting. An additional 15 people complained about significant conflicts with housemates. Other complaints included concerns about food, activities, and restrictions of communal living. People having their own rooms in care facilities expressed greater satisfaction overall. Many stated that they would like to have their own room. In all, 16% of the people living in licensed facilities were dissatisfied with their living situation. The desire for a place of one's own remains a dream for many of these individuals, as the overall number of people using supported living services (24%) remains relatively static throughout the five counties. It should be noted that the LQA visitors do not assess barriers to supported living arrangements, but merely noted that the individual's expressed preference for those services had not been realized.

Reductions of hours were cited by individuals receiving supported living services, or doing without supported living services. Specifically, these complaints related to overall reduction of hours, and unavailability of support during the medical appointments. People who were not receiving services and who expressed a need for services had typically encountered a new problem in their lives, such as a rent increase or medical concern, and needed assistance before their problems became a crisis.

Visitors also found several people in marginal living situations. Four people were living in motels, a married couple living in a condemned trailer, and five people were facing eviction or in temporary housing. These numbers are small, but are all related to the escalating costs of housing in this catchment area.

Residential Services for Children

One person aged out and was in need of adult placement. Seventeen children were living in Foster care.

Day Activity Services

Complaints about day programs, most commonly that they were boring were observed again this year. Visitors also found that people who had changed from site-based to community based programs typically expressed a much higher satisfaction with the new services. Many people expressed that they would like flexibility with their day program schedule. Many people expressed an interest in changing day programs to try something "new". Services for seniors in day activity services increased and individuals were satisfied with those services.

There were 79 individuals visited who were not receiving day time services, 9 specifically mentioned that they had rejected day program services as programs as boring, stigmatizing, or unable to meet their activity preferences. Dissatisfaction was slightly higher in Stanislaus County, and lowest in the three mountain counties.

Forty-five people expressed a desire for employment or better employment. Twenty-one people wanted a better job, or more hours on their current jobs. In total, 25% of the people visited expressed dissatisfaction with daytime activities. Twenty-two people expressed that they wanted a “real” job and not be part of a “job crew”. Fourteen people had specific jobs in mind but were frustrated with the lack of support to obtain such jobs. After several years of this same trend, there is a strong indication of significant problem in the day time services currently being offered to people who use regional center services. Because these complaints are area wide, this trend suggests systemic issues.

Six percent of the people visited who used day program services also had jobs as part of their day program services. Some day programs were also offering flexible hours, including evening activities, to better meet individual preference and social needs. Four percent of those visited were participating in a senior program and were satisfied.

Medical

Health emerged as a major area of individual concerns as in previous years. Service Coordinators were almost always aware of medical needs, and visitors observed some very carefully organized and managed services for individuals with complex needs. Difficulties were most often systemic or attitudinal barriers, and similar to previous year results. Needs included adaptive equipment or equipment repairs, follow-up with specialist, wellness activities to maximize health such as smoking cessation and weight loss. Access to services not covered by Medi-Cal, including medications, or not provided with sufficient frequency, such as glasses or hearing aids, was also a concern. Need for a dentist was also an ongoing issue, but more frequently noted by people who had specialist needs, such as anesthesia. Individuals who received supported living services stated that their worker was not allowed to take them to appointments, but could meet them at the appointment. The scheduling and actuality of getting to the appointment proved difficult for many individuals. Some people stated that they needed support during the doctor’s visit to help with understanding the process and what was being discussed. The majority of people who lived in care homes were not aware of their medical needs. Many care homes have a doctor come to the care home periodically to see a great number of people at once. Licensing requires that each home monitors each person’s medical needs and therefore the person isn’t often an active member or included in their healthcare regiment. Tasks such as scheduling of appointments, medication changes, or discussion of the medication and side affects are often done at the convenience of the care home and or doctor.

Four individuals or their foster parents expressed frustration in getting assessments for needs related to the possibility of neurological problems or autism. These foster parents did not have an established relationship with regional center service coordinators, and did not see the regional center as a significant resource to their family member.

Families with Dependent Children

Visitors met 9 individuals who had children under the age of 18. Again, visitors are finding an increasing success in supporting families when one or both parents use regional center services. Seven people had expressed their desire for information about their child's well being. The children had been either living in foster care or had been adopted. Supporting people to do this was an issue.

Spiritual Needs

Thirty-one people identified unmet spiritual needs. Barriers included transportation, distance from preferred church, and no staff support to attend preferred services. One person complained that they had to attend to the church of their provider's choice. Like other cultural sensitivities, there is varying valuing of spiritual activities among providers, and varying accessibility within faith organizations. Visitors also noted some homes where individualized support was provided effectively so that consumers could participate in their preferred faith communities. It was not clear to visitors why some homes provided that individualized support while others did not.

Summary Results by Category

Choice

The "Choice" category includes information about the ways that individuals identify their needs, wants, likes and dislikes; how they make major life decisions; how they make everyday decisions; the role they have in selecting providers of services and supports; and how their services and supports change as wants, needs and preferences change.

The majority of individuals visited were still satisfied with their choices. As discussed previously, the trend of dissatisfaction with the choices offered in care homes and day programs has continued. Communication continues to be a barrier to making choices. Support staff often relied on ability to interpret the individual's personal communication based on long-term relationships, without assistive tools, and often did not express concern about the dependency that engenders. Five individuals had restricted access to assistive communication devices, because they were unavailable in some environments or direct care staff was not trained in their use.

Most people living in their own homes expressed satisfaction with the choices that they made in their lives. Problems with limited choices were typically related to food and activity options. Other concerns related to room decorations, roommate selection, and service providers. Six people, who were otherwise unrestricted in their right to make decisions for themselves, stated that they didn't agree with decisions that are made for them by family, staff, and in four instances, by their Service Coordinators.

Relationships

The Relationships category includes information about individuals' friends and caring relationships; and whether they have community supports that can include their family, friends, service providers, other professionals, and other community members. Relationships are always central to the quality of an individual's life, and are frequently areas of concern.

Visitors found that many people in all five counties expressed the desire and or need to connect or re-connect with family members. Many did not know how to do that and did not have support to do that. Many people talked about losing a loved one and wanted to share their feelings of loss with someone. Many relationships were based on people they saw each day at a day program or care home. Many people said they didn't see any friends outside those places. Most people considered their care providers and service coordinators as their friends and/ or family.

Fifteen percent of the people visited identified relationship concerns. Twenty-two people complained about problems with roommates. While most of these complaints related to personality conflicts, some complaints included fear of assault and frequent sleep disturbance. Three people expressed fears about a classmate at day program. Thirteen people wanted to visit out-of-area family. Three people wanted phone numbers to call a family member, five wanted addresses to mail letters/card, and seven people wanted help locating siblings. Ten individuals expressed loneliness and a desire for friendships. Two people wanted to visit their former homes and reconnect with support staff they had known in the past. Behavioral concerns were cited for six people, as significantly interfering with social relationships.

When housemate discord involved violence, the violence was still viewed as a behavioral issue rather than an abuse issue. Again, visitors observed that there did not appear to be much concern regarding emotional well being and traumatic stress when assaults involved housemates who both used services, or between individuals using the same day program services.

Lifestyle

Lifestyle is a broad category, including if the individual is part of the mainstream of the community; if their lifestyle reflects cultural preferences; if they are independent and productive; if they have stable living arrangements; if they are comfortable where they live, and if children who are regional center clients live at home with their families. In part because of the range of the lifestyle category, the greatest number of concerns was identified under this category. Consequently, in the summation bar graphs, lifestyle concerns are broken down into three subcategories. As in previous years, issues ranged from small changes to lifestyle reordering.

Dissatisfaction with day services was 20% this year. Complaints were split between dissatisfaction with available day programs and the desire to be employed instead of having traditional day program services. Six percent of the people visited were employed through day programs. Five percent were competitively employed or using supported employment services.

Other issues included more time in the community and more activity overall. Nineteen people wanted to spend more time in the community; seven people specified weekend and evening activities. Twenty-five people wanted to take classes at community college or vocational school. Thirty people wanted specific skills training, such a learning to cook or read.

Cultural needs were identified in visits with 20 individuals. A familiar pattern, visitors observed that providers were generally making efforts to build cultural elements into the services they offered through menu offerings, activities, and home decor. American Anglo continues to be the dominant culture. No community care facility visited used Spanish as the common language within the home.

With the exception of 20 individuals visited, people were settled in stable housing. The majority of people visited were in clean, safe, and reasonably comfortable settings. Sixteen percent of the people in licensed facilities were unhappy with their homes, and 4% specifically requested a change in their home. As in previous years, most complaints related to limits in choices, conflicts with housemates and providers, and the desire to live in other communities.

Twenty-four percent of the people visited this year were either living independently or receiving supported living services. Of this group, 20% had dissatisfactions with their living circumstances, usually related to poverty issues such as the small size of their housing units or substandard housing.

Health and Well-being

Issues and the number of people expressing concerns have been similar in aggregate data annually. Individuals living independently or with supported living services almost always knew about 911 and how to get assistance in an emergency. Eleven people did not feel safe in their neighborhoods. Staff were able to specify how they would recognize that an individual who does not use words was ill or hurt. Nine people were fearful of assault from other people who use services.

Twenty-nine percent of the individuals visited identified one or multiple wellness or health concerns. Ten people asked for help in improving their health through exercise, diet, and smoking cessation. Seven people had problems with repair or replacement of durable medical equipment, most frequently wheelchairs. Two people were in need of specialists, including neurologists. Two women had OB/GYN needs. Eight people reported problems with medications, including nausea, vomiting, excessive sleepiness, and dizziness.

Other chronic health problems, such as stomach pain, and feeling tired were identified for 9 individuals.

Rights

The Rights area of the LQA gathered information on the individual's exercise of personal rights as a person who uses services and as a citizen; whether or not the individual is free from abuse, neglect and exploitation; if the individual is treated with dignity and respect; if the individual is receiving appropriate generic services and supports; and if the individual has advocates or access to advocacy services.

The understanding that individuals had regarding personal rights varied widely, and was not necessarily related to the degree of supports being provided to that individual. Visitors used a copy of the client's rights poster distributed by the Department of Developmental Services to talk about rights. While concept of rights was an abstraction for many people, people were

typically able to understand the specific examples used by DDS to illustrate rights. As in previous years, most visitors observed respectful and even affectionate interactions between individuals and the people who support them.

Twenty-one percent of the individuals visited identified concerns in exercising their rights and responsibilities again this year. Eight of those people wanted to learn to speak up for themselves and to exercise their rights more effectively. Seven individuals specifically requested involvement in People First or self advocacy groups. Two people wanted rights and IPP training. Greater control in life was a frequently expressed desire, especially control over finances. Three people wanted to change payees, and six of those people wanted to receive their money directly. Other ways that people wanted more control related to personal choices, such as with clothes, without control by family or service providers.

Four individuals alleged violations of their rights that were potentially abusive or exploitive. Two of these complaints involved support staff. The remainder of the complaints related to conflicts with housemates, people at day programs, or personal relationships. One person was involved in a legal case of alleged misconduct by an executor of a trust fund. Ways that people felt their service rights might have been disrespected included things such as having a “boyfriend or girlfriend” relationship, household curfews, phone use restrictions, and bed times. Two people felt that their needs were neglected by care home staff. Six people complained about care home staff speaking to each other in a language other than English. Most people visited were using generic services and supports successfully, most typically public transportation, financial aid, and housing assistance. Twelve individuals identified problems with generic services, many of which needed advocacy assistance. Problems included straightening out SSI payment difficulties, denial of services by Dial-a-Ride, applying for Section 8 housing assistance, getting personal identification and records, and support from the junior colleges disabled services.

Legal services were needed by three people dealing with landlord/tenant issues. Two people needed legal assistance with estate issues, and two people had personal injury legal concerns.

Ten people were not happy with the treatment they received from their VMRC service coordinator and requested a change. Some of the issues raised were matters of personal preferences, for example wanting quicker responses from the service coordinator. Seven people had not met their Service Coordinators at the time of their LQA visits.

Five people disagreed with decisions that their Service Coordinators made. The majority of complaints fell into three areas – frequent turnover of Service Coordinators, slow response, and not feeling respected. Two people complained that their Service Coordinators would get angry if comments were written into the LQA summary.

Satisfaction

The Satisfaction area of the LQA addresses whether or not individuals achieve personal goals; if individuals are satisfied with services and supports; and if individuals are satisfied with their lives.

Satisfaction is difficult to assess, particularly for people who do not use words to communicate. But for the most, people appeared to be content with their lives. People generally lived in attractive and comfortable settings, and felt that they were supported with care and respect. Almost half, 43%, of the people visited identified no follow-up needs at all. Many of the issues that were raised, such as wanting more contact from family, were most probably not resolvable through regional center services.

Hearing about people's dreams is an especially enjoyable part of LQA visits. This year, 63 people shared future hopes. Lots of dreams included traveling. People wanted to get married, buy their own homes, drive their own cars, and achieve career goals. Some dreams were well within reach of the planning team, such as a visit to Disneyland or going camping.

As already discussed, people talked about wanting different kinds of services, new day programs, different workers, and people who could help them achieve their ambitions. In addition to those issues already discussed in this report, 25 people expressed dissatisfaction with one or more support staff or service agencies. Most frequently, those complaints related to the reliability and quality of supported living services, IHSS services, and to the absence of any desired services.

Conclusion

As in previous years, the overwhelming conclusion of the data is that people are, for the most part, being supported in ways that meet their needs respectfully and effectively. The impact of low income is greatly ameliorated by support networks.

A significant finding in this year's data relates to multi-cultural services. Meeting the cultural needs of individuals who are not English speaking continues to be a significant challenge within the service system, for day services, employment and residential services. Other cultural issues, such as same sex personal care, preferred music and food were also individual concerns. Conversely, many English speaking individuals felt some care providers were talking about them in their native language (not English) which caused anxiety and other issues for the individual.

Visitors observed efforts to respond to the increasing dissatisfaction in day service options through increased employment and variable schedules. Overall, 20% expressed dissatisfaction with day services again this year, a trend that merits serious consideration.

Visitors observed that many individuals wanted a sense of family and connection to other people. Visitor's shared that it was an honor and privilege to visit with individuals who were open to sharing their stories with them.

